

**The Alzheimer's Podcast: Navigating Rough Terrain with The Dementia Sherpa**  
**[BONUS: The Pfizer Story](#)**

Christy: *What I woke up to this morning, Phil, was the front page of The Washington Post. Top story: "[Pfizer had clues it's blockbuster drug could prevent Alzheimer's. Why didn't it tell the world?](#)" I'm still--this is, you know, so many hours later--I'm still having a hard time talking about it without getting really emotional about it. I did a double take when I saw the headline. I read this story and I burst into tears.*

Phil: Interesting. I didn't. I read the headline, read the story, and somebody wrote to me basically the minute I had finished the story, and said, "Isn't this the worst thing in the world?" And my reaction was, I thought the headline and the top of the story were hyped a little bit, and that I could understand the perspective of the drug company executives. The data as I read along and the research as I read along seems really sketchy to me. So I didn't immediately go to, "How dare they not do that drug trial and spend that \$80 million!" And blah, blah, blah, blah, blah.

What I did get angry about, and what I continue to be angry about, is that they didn't share the research with others and they kept that--they chose to keep that--a secret, the research. And that to me is criminal. Somebody should go down because... You could make a fiduciary decision and say, "I don't think this is gonna work for our company based--because of whatever reasons." But you better be out there right away saying, "Hey world, look at this! This is a possible avenue for you to pursue to possibly find a treatment or a cure for this thing." And the fact they didn't do that just boggles my mind. Does that make sense?

Christy: *Yeah. We talked however many episodes ago where I s--or no, it was [a blog post that we did together](#)--and I said I had made the conscious choice about 15 years ago after my heart was broken too many times with drugs not making it through clinical trials. And so I had made the conscious choice to see what I could do to make life better for people living with Alzheimer's or other neurodegenerative conditions and their families in the here and now. People who are affected here, now--how can I make a positive difference? How can I have an impact there? Rather than getting heavily invested in the research, because I'm a squish; my heart was broken too many times. And I think, you know, reading this, it brought a lot of that back because this again, this drug is an anti-inflammatory and*

*the last straw for me 15 years ago was an anti-inflammatory drug that the trial was ended because there were some people who died because of it, but it was a very promising area of research. The Alzheimer's Association put out [a statement](#), and this is via Twitter. It says, "The Alzheimer's Association believes very strongly in sharing data for the benefit of the entire research field and ultimately for the benefit of people with Alzheimer's disease. 'Any science that has promise for Alzheimer's and other dementias and is not genuinely pursued or shared with the research community, does a disservice to the millions of individuals facing the disease today and in the future.'" And that was by Dr Maria Carillo, who is the Chief Science Officer for the Alzheimer's Association.*

Phil: So glad I'm associated with them. I mean, that's exactly right.

Christy: *Yeah.*

Phil: I mean, if you read, when you continued reading the story, the research that they hyped in the headline really was sort of, is attenuated the right word? It was looking--it wasn't looking at actual people. It was looking at records from insurance claims and it really felt quite a distance from, *This is the block-- this is the cure everybody's been waiting for. This is the molecule everyone's been waiting for.* So again, it didn't strike me as criminal that they didn't pursue it. I agree with the Alzheimer's Association: it's criminal that they didn't share it.

Christy: *Yeah, I think that that was the point. That was the point. And--*

Phil: But that's not what the story started. I mean, that's not as sexy. And here I am a former journalist and some would argue a current journalist, you know, critiquing the story. I mean, it wouldn't have made a very sexy story saying these people didn't share their research, right? That's just, Uh, okay. Who cares? I mean, you know, a sexier story is, These people had the cure and they chose not to pursue it.

Christy: *Well, that is not what it says, though.*

Phil: Well, it implies it at the top of the story. You have to read along to say what, to see what the actual data was, which--

Christy: *Okay, I'm just going to point out right now this story was front page of The Washington Post.*

Phil: Yes, it was.

Christy: *Phil is a former New York Times reporter and there's been known to be a little competition and tension between the two organizations. Just gonna throw that out there. But going back to your beloved Times, this for me--and I tweeted this--it felt like a one-two punch to me this morning, because I read that story first in the Post and then I clicked over to The Daily, which is the New York Times' podcast that I listen to every morning. And the episode this morning is entitled, [This drug could end HIV. Why hasn't it?](#) And I highly recommend that [episode] and I'll put that podcast in the show notes too. The choices that companies make have impact on real people, on real humans. And I guess, you know, in order to be functional and effective in doing what I do--of course I connect to my clients, but I tend to be, I think, very compartmentalized. I can't think about all of the losses that I've experienced along the way. Or I don't think I could continue to do this. When I say I've worked with over 1,500 people living with dementia, I don't--I may be the only one who hears it, but that's 1,500 obituaries.*

Phil: I can't imagine. The thing that makes me so amazed about you, and so grateful to be, I believe, your friend, is I can't imagine--and you've talked about this a little bit, touched on it a little bit--the strength that one needs to be able to deal with inevitable death over and over and over again. And, I couldn't do it. I can barely think about it. And actually one thing I was thinking that we could have talked about is next week I have, my sister and I are going to meet a childhood friend who is in hospice who wants to

see us. And I'm--uncomfortable isn't the--uncomfortable describing my dread of doing this, but my recognition that I kind of have to do it.

Phil: But you know, I can't imagine doing this work over and over and over and over again and waking up to that headline. I mean, the headline? Believe me, when I saw the headline, I was infuriated, right? Because it sounded like they had gold standard evidence and it was just a financial decision and they decided not to go for it. The story was more nuanced, as most stories are. So I didn't end up thinking, God, they should be thrown in jail for not deciding to do that! Even though if this were--if those very initial findings were true, it would have helped me. Probably, right? 'Cause they were [unintelligible], they were not just finding that it stopped Alzheimer's, or that it prevented Alzheimer's. They were finding that it slowed it. So it was a treatment, potential treatment.

Christy: *Yeah.*

Phil: My journalistic skepticism said--and maybe this is why I wasn't so destroyed by Biogen--I mean, [the trial that I was in](#), because I always felt like it wasn't going to help me. You know, but you're coming at it from a perspective of, *It's not just you, you big fool. It's all those others, you know?* Yeah, I mean, I always talk about my advocacy today is not for me. Even though I pulled up a little sign at the Alzheimer's conference saying, "I advocate for me." But it's for my nieces and nephew and their kids, 'cause I don't want them to have to miss this. I'm--it's too late for me. I know that. And I bake that into my, my everything. But gosh, we gotta stop this. And stopping it means sharing any, sharing any scientific information, no matter how vague it is, with the broader world. Because somebody could say, "Oh, that's really interesting. I want to pursue that." And we're now at the place where, because science reveals, because Congress is getting with the program and understanding the enormous cost that we could face if we don't solve this. It's understanding that they need to test, and there's money available for other scientists to say, "That's a really interesting theory. I'm going to pursue that."

Christy: *Mm hmm.*

Phil: So yeah, I couldn't put myself in your place. And I don't know how you do it every day, truthfully. I think, you know, you have amazing strength. And you've still got a snark to you, too! We recognized each other right away, remember? "If you, if you have nothing nice to say about anybody, please come sit next to me." I think that was one of the first things I said to you.

Christy: Yes.

Phil: So I don't, I don't know how you do it, Christy.

Christy: *Well, I am blessed, I am lucky, I am privileged to get to do the work that I do. Because I get to work with people and hear their story and, I hope, make at least a moment better. It's really important, and I do feel like it's the reason I'm on this planet. That said, I'm happy to find a different life purpose. I'm okay with this being cured. I'll figure out something else to do. I've got a whole bunch of books I'm really interested in reading. You know, I can always entertain myself. But I think, you know, it's such--so most people that I meet that aren't in the profession but just regular people, maybe they've had a parent who has been through this or an in-law. But for most people it's like one person. Sometimes, certainly, there are more people in a family, but usually it's not in the double digits.*

*And so when they see a news story like this, or when they think about other people going through this, I do feel like they have empathy and say, you know, "Gosh, that's terrible!" But I can attach names and faces to the implications of somebody or a company being so selfish and so self-centered and so short-sighted and so unconscionable to not share the research. I see faces.*

Phil: Mm hmm.

Christy: *And it pisses me off. You know, Pfizer, I don't know--I could do a Google search, but I guess I'm lazy. I'm not doing it. I could see [what their profits were for last year](#). Do you have a guess? I really don't know.*

Phil: It talked about it in the story. I mean, they--

Christy: *Oh, did it? Okay.*

Phil: They've made billions off this drug.

Christy: *Okay. So, multiple billions.*

Phil: So, when you put it in that context. Put it in that context, and I did. And then I said, *Well, eight hundred, 80 million to do a trial isn't very much money.*

Christy: *In context of having made billions.*

Phil: Having made billions off it.

Christy: *Right.*

Phil: There was also a whole section about how the fact that drug's about to go off patent and blah blah, blah, blah.

Christy: *Right, right.*

Phil: I mean, you know, the drug industry, we could, if we wanted to talk--

Christy: *We could, but I'm going to pull it in. The reason I brought that up, though, is because--and the reason that it wasn't readily coming to mind is because I sat through a presentation today. Our speaker was the public policy director for the Alzheimer's Association Oregon Chapter. So I've been looking at numbers all morning. Here's one that I jotted down that I thought was super duper interesting. So the NIH, the National Institutes for Health, in 2011--so the [NIH does funding for research](#). And unfortunately there's--well, in my view, unfortunately, there's a whole lot of public-private partnership because the public part isn't very well funded. And here's what I mean by that. So NIH, which would be public funding, in 2011 Alzheimer's disease had a budget of \$448 million for research. \$448 million. Now, because people like you, Phil, who are advocates and out there talking about this every chance you get--now, eight years later, for 2018--now, the budget is all the way up to \$2.3 billion. And I don't know what \$2.3 billion is for Pfizer; I'm guessing they clear that amount of profit in a year.*

Phil: Yup. Yup.

Christy: *We are talking about a condition that doesn't have a cure that affects real people and real families every single day. You know, that's just one piece of it. That's just on the budget side of it. But you know, for 2019, nationally in the US, it's expected that [16 million people will provide 18.5 billion hours in unpaid care](#). So that's roughly a cost of \$239 billion for 2019 for the care of folks with Alzheimer's disease or related or similar neurocognitive disorders. So not only is it \$239 billion in the cost of unpaid care, all of those 16 million volunteers, so-called volunteers, they're very unlikely to be working another job outside the home, a paid position. So they're not paying into Social Security, they're not paying into their IRA, they're not beefing up their 401k, they're not getting 401k matching funds. But their stress level is higher. They are more likely to push aside their own health concerns. I mean, this just--any way you slice and dice it, any thing that isn't done to help figure this out, to at least come up with a treatment--and I think that's the bare minimum we can ask*

*for, is an effective treatment. But I very much like to see a cure. Just, to me it really feels unconscionable. And then you throw in a drug company--and I'm really not a conspiracy theorist nut--but you throw a drug company into it that's withholding research that could be helpful and is, you know, no doubt making terrific profits. And--I'm just going to take a wild guess--benefited from the corporate tax cuts that happened last year. It just, it, yeah, it burns my britches. Big time.*

Phil: It should. It should. You know, I'm listening to you and getting angrier.

Christy: *You're welcome.*

Phil: I don't need that anger, thank you very much.

Christy: *Yeah, I know. Usually--just for listeners: usually, this is not the effect I have on people with Alzheimer's. Usually, it's like the other way around. They start angry and then I make them feel better.*

Phil: It's interesting. I would love to hear what others who are living with Alzheimer's, their reaction. Maybe I will poke around and see what others'--

Christy: *Yeah!*

Phil: I mean, it just may be that I--you know, journalists carry a certain....To be a journalist, you carry a certain level of skepticism in you. It's just part of your DNA. So it may just be that I carry that skepticism around with me. And that I should have been angrier. I mean, Tim's reaction--you asked me to ask Tim [Phil's husband], and Tim's reaction was, "The whole thing just makes me really, really angry. That's my two cents." So, I'm weird. And it sucks.

Christy: *Well, I wish I had asked you about Tim's reaction before I went off on my big Blah, blah, blah, blah, blah, because Tim was just very succinct and to the point!*

Phil: Yeah, I mean, I see where you're coming from. And I see where I'm coming from, and I'm sure the truth somewhere in the middle. But I think everybody can agree that the fact that they didn't share their research is why they should be in jail. I mean, that's the thing that just really burns me, is again, you could make financial, fiduciary, blah, blah, blah, decisions up the wazoo, but you have no reason not to trot out your scientists in the next international conference and have them say, *Hey, we see something interesting in this data. Somebody should pursue it.*